

Connectedness – Up Close and Personal!

Beth Moulam and Emma Green

1

www.bethmoulam.com
<http://www.emmagreen.com.au/>

Hello, can everyone hear us OK?

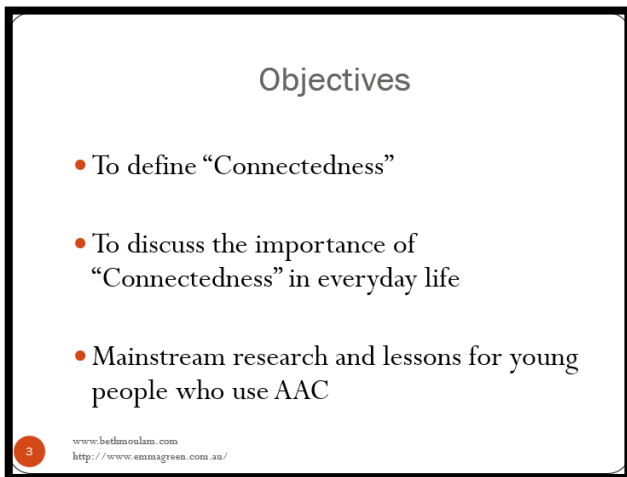
Good

My name is Beth Moulam, this is Emma Green, and we are here to talk to you about something that means a lot to us both, Connectedness.



Before we begin we want to explain that although we live at different sides of the world we have been friends for over 6 years. I live in Surrey. Emma lives in Queensland, Australia.

Our friendship has been built through using technology and spending time together both in England and at ISAAC in Barcelona.



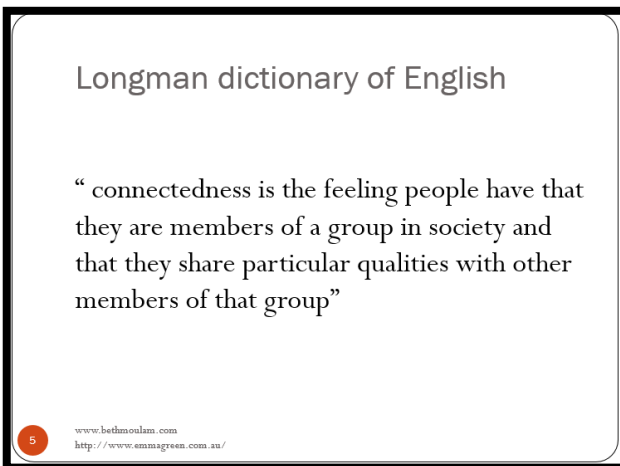
In this presentation, we are going to explore how both the UK and Australia understand the word, connectedness. Does it mean different things in our two societies?

We have looked at research into connectedness for young people who use AAC. We have considered what connectedness means to us. And we will share some of the ways we have made it happen for us in our everyday lives.



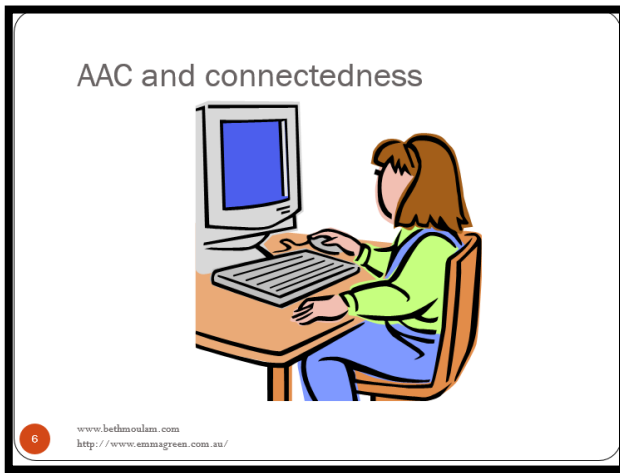
Everyone is connected, one way or other. Maybe as a Mother or a Father. We could be a Sister or a Brother. Or just a friend to someone, a mentor, a sports coach or an employer. No

matter who we are, we are all connected somehow.



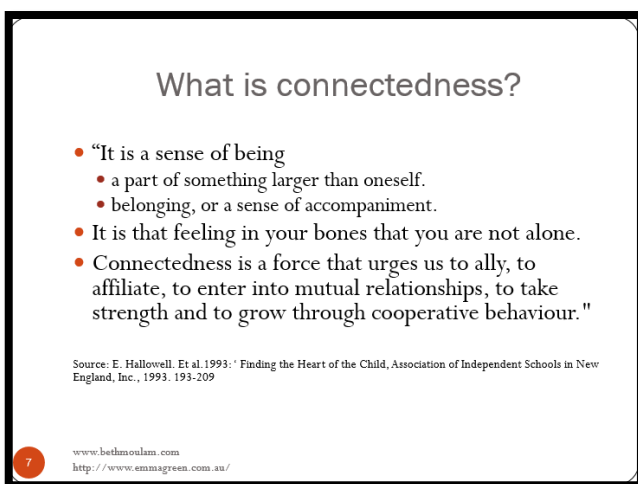
So. What is connectedness? The Longman Dictionary of English defines "connectedness as the feeling people have that they are members of a group in society. And that they share

particular qualities with other members of that group".



I have really enjoyed researching into this topic. Some research implies connectedness is how people are connected by technology. I've found a little research

specifically around teenage connectedness. And even less on AAC and connectedness. I couldn't find any on teens and AAC. The research I did find doesn't talk about communication but without communication connectedness couldn't happen. Here are the views of 3 researchers that summarizes what I found.



Hallowell suggests connectedness is that feeling we have of belonging, or the sense, no matter where we are that we are never alone. This comes from feeling welcomed

by others in school, home, work and the wider community. The need for connectedness makes every human being want to make friends and build meaningful relationships.

Karcher (2011)

- Measures teenage connectedness by “their activity in in various places and how we care for people in our social environments”
- This is the social support from
 - Peers
 - Friends
 - Adults
 - Media
- And belonging through social relationships with
 - Family
 - Close circles of support

Karcher, 2011, The Hemingway Measure of Adolescent Connectedness

www.bethmoulam.com
<http://www.emmagreen.com.au/>

8

Karcher uses the Hemingway measure of adolescent connectedness to evaluate the social support teens get from peers, friends, adults and the media. This focuses on achieving

a sense of belonging through social inclusion. And attachment, the important safe childhood relationships to key family members and a close circle of support we all need.

Balandin (accessed 2013)

- “satisfying social relationships are important for good physical and mental health”
 - Yet People who use AAC
 - Lonely
 - Over reliant on families
 - Have difficulty forming relationships
 - Few work opportunities
 - Poor access
- Restricted by ‘gatekeepers’

<http://www.dart-gbg.org/public/anpassningar/Loneliness%20and%20AAC.pdf>

www.bethmoulam.com
<http://www.emmagreen.com.au/>

9

In her research, on loneliness and friendships with people who use AAC, Balandin suggests younger people who use AAC may feel lonely due to reliance on family.

The difficulty forming relationships inside and outside of school. Their future limited work opportunities. And poor access to friends sometimes because of others being unwilling or unable to help them meet up with friends or be in an environment to make friends.

Balandin (2)

- Barriers to connectedness
 - Over protective families
 - Lack of time and support to train communication partners
 - Not enough support to develop use of effective communication systems
 - Lack of privacy

10

www.bethmoulam.com
<http://www.emmagreen.com.au/>

Balandin's work also suggests barriers to connectedness can be over protective families. The time and lack of skill of communication partners to help people who use AAC to develop

relationships. And insufficient support to develop effective use of communication systems ongoing. A further barrier can also be the lack of privacy experienced by those of us with complex needs. We will come back to this later.

Connectedness research

Connected



Dis-connected

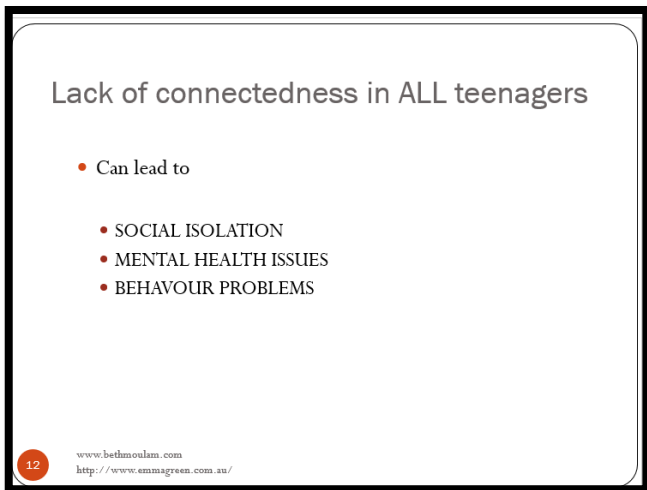


11

www.bethmoulam.com
<http://www.emmagreen.com.au/>

Throughout the research there was proof that all teenagers who are connected at home, at school, socially and to themselves are more engaged, achieve more and stay out of

trouble.



Having little or no natural speech can create huge problems including social isolation, mental issues and behavioral problems. Exactly the same issues when there is

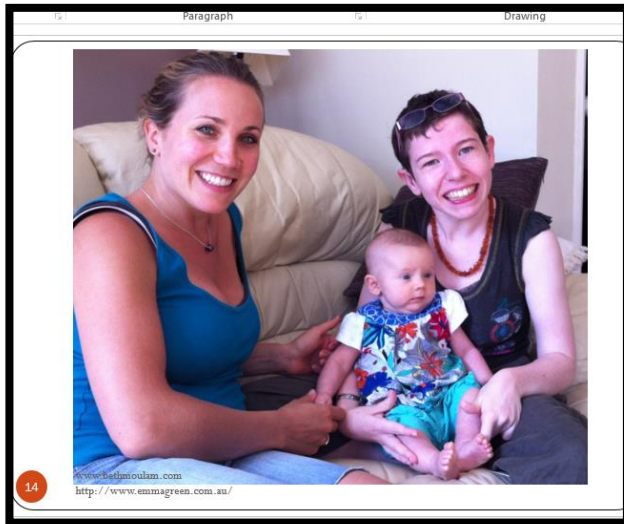
a lack of connectedness for all teens. The main difference for those of us who use AAC is that it can be more challenging to explain we are lonely. To share we have things on our mind. And in some cases we may act inappropriately if we can't explain. If we need trusted communication partners to explain our concerns to, we also need trusted and well trained staff to support us to put it right.



Connectedness is not just about being asked questions and giving answers, we do not want to be passive communicators. It's about meaningful and purposeful conversations. Having a functional

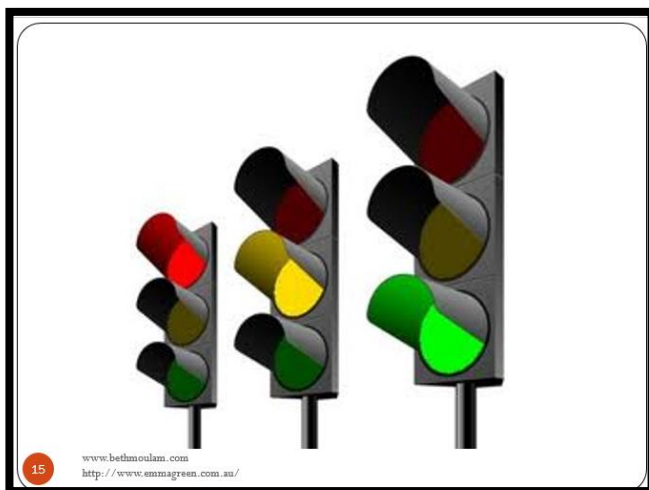
dialogue. Providing direction and the ability to be creative spontaneously. We want to ask questions, and go with the flow. This means we need well trained and supportive communication

partners. Clearly there is a theme coming through here, the right communication partners are vital.



Some people are connected straight away. Others need time to connect and understand people, especially those of us with AAC who need support in day to day situations. Both Emma and I have had our ups

and downs with being connected. We know this only too well what happens when relationships fall apart or cannot be started.



Throughout our short lives, both of us have experienced low and high expectations from extended family, professionals, teachers and other staff. Some people have


been incredible, others not so. We have met those who would ask a question but couldn't be bothered to wait for a reply. We both know people who made us feel good about ourselves and those who ignored us when we needed or asked for help.

Emma is going to share her experiences of being connected.

Emma, over to you.

Emma


- Cl



www.bethmoulam.com

17

- What animal can jump higher than the Sydney Harbour Bridge?



www.bethmoulam.com
<http://www.emmagreen.com.au/>

17

- All animals because bridges can't jump

www.bethmoulam.com
<http://www.emmagreen.com.au/>

18

My Multi Modal Communication

- PODD Communication Book
- Tobii with Eye Gaze
- iPad (Tap Speak Sequence)
- Eye pointing
- Facial expressions
- Signs
- Gesture and vocalisations

www.bethmoulam.com
<http://www.emmagreen.com.au/>

18

Being connected is important


- Family
- Friends
- Role Models
- Therapists and educators
- New connections e.g. Boccia Team
- Facebook network

www.bethmoulam.com
<http://www.emmagreen.com.au/>

20

Morgan

- Text messages
- Facebook



www.bethmoulam.com
<http://www.emmagreen.com.au/>

21

Good friends and role models

- Include me
- Inspire me
- Understand me
- Motivate me

Without connections I feel

- Angry
- Upset
- Annoyed
- Depressed
- Worried
- Lonely
- Disempowered
- Frustrated
- Uncomfortable
- unmotivated

Good connections make me feel

- Safe
- Terrific
- Comfortable
- Empowered
- I have control
- Included
- Sense of belonging

Some of the challenges

- Credit on sim card to send sms from Tobii
- Facebook wont load
- New PA
- Meeting new people
- It takes time to learn how I communicate
- Frustration
- Emotions
- *Back up is so important

Hopes, Dreams and Aspirations

- College and University
- Strong connections will help me achieve my dreams
- Over to you Beth!!

EMMA speaks first

BETH

Thank you Emma. My experiences and feelings are very similar so I am not going to

repeat what Emma has said. I do want however to expand with one example of building new connections.

University of York



- Built environment
- Disability support team
- Support Agency
- Academic Staff
- Family and friends in York

27

www.bethmoulam.com
<http://www.emmagreen.com.au/>

Emma mentioned her dream of going to University. I am imminently starting at The University of York and have already moved into halls. From the minute I first contacted

York, I felt a connection with both the academic and support people I met. The campus is accessible and I am already loving living in halls.

Practical Strategies for Connectedness

- Families
- Modelling good communication
- Access to communication resources
- Friends
- Social networks
- Role models and mentors
- Privacy
- Gatekeepers

28

www.bethmoulam.com
<http://www.emmagreen.com.au/>

Emma and I promised to share with you some of our practical strategies to develop social connectedness as teenagers who use AAC.

Families

- Communication competence and confidence is built around family support
- Connectedness through secure family relationships
- Making time to communicate
- Ensuring the resources needed are always to hand

29

www.bethmoulam.com
<http://www.emmagreen.com.au/>

First we are both fortunate to be part of supportive families. We have access to a wide range of communication resources to meet our needs in varying situations. But, we

know that families come under huge pressure with all constant needs. It could have been easy for our families to stay at home, not to have fought for the resources we need or not given us the time to express ourselves. Feeling secure at home has helped us to be more confident in the wider world.

Modelling good communication partner skills

- With
 - Extended family
 - Friends
 - Support staff
 - Professionals (outside of SLT)
 - Wider community

30

www.bethmoulam.com
<http://www.emmagreen.com.au/>

Throughout our lives our parents and other close family members have modelled good communication strategies. They have trained others to work with us, given us the tools and

confidence to train others. We are not aware that training courses are available for those who support people who use AAC. This means our future support only be as good as we can make it. We know getting a communication aid is the beginning of communication but it needs life-long support.

Access to communication resources and communication partners

- Equipment charged and ready to go
- Always on hand
- Kept up to date with changing vocab and software
- New staff trained

31

www.bethmoulam.com
<http://www.enmagreen.com.au/>

Besides maintaining our equipment we need access to the right vocabulary to share our feelings and experiences. This vocabulary needs to grow with us. In school this was

supported by staff, in adult life it's our responsibility, and that of our families. Life doesn't stop when we leave school. As we move on it will become the role of paid staff, such as my university support team, who need to be trained for what they are expected to do.

Communication partners

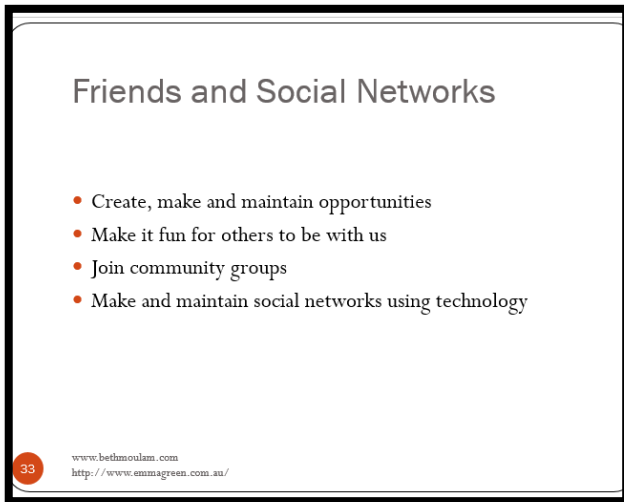
- Listen
- Give us eye contact (be on our level)
- Repeat or re-phrase what we say by agreement only
- Ask only one question at a time
- Know when not to speak and how to wait
- Be (and look) interested
- Know how to repair conversations.

32

www.bethmoulam.com
<http://www.enmagreen.com.au/>

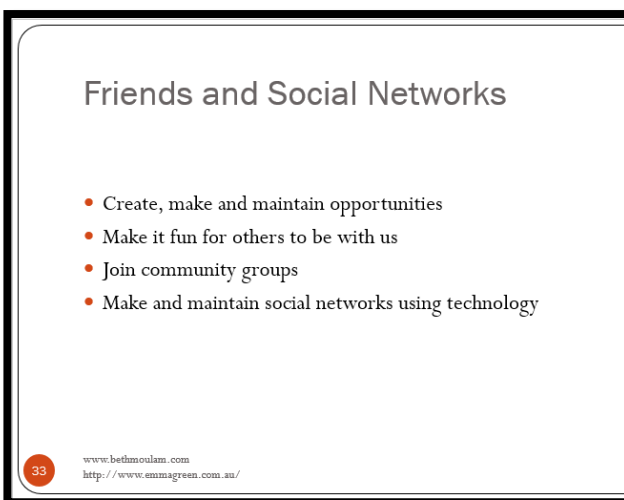
Both of us have access to trusted people, not just family, who know how to listen to our concerns and support us in agreeing a course of action. I also have regular counselling. I find the ability to talk to

someone trusted and non-judgmental who is not part of my everyday life essential in making sense of things.



Supportive and well trained communication partners are essential. For us a good communication partner listens and doesn't interrupt. Gives us eye contact by getting down to our level. Repeats or rephrases

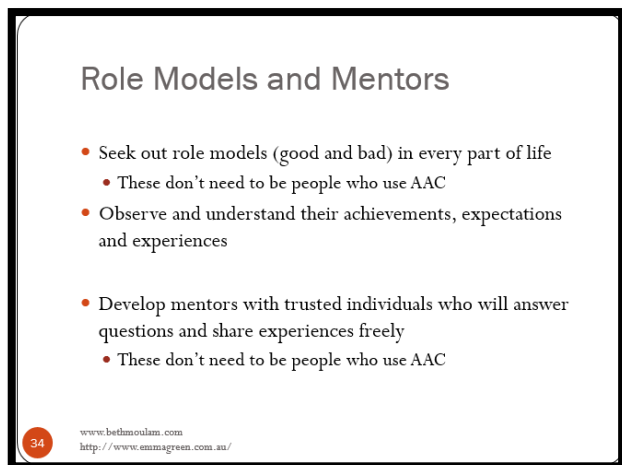
what we say only by agreement. Knows when to be quiet and how to wait for us to compose what we want whilst remaining engaged. If you start looking around the room we might think you are bored! The list could go on but this is for starters.



Like everyone else we need friends. This often doesn't happen naturally. Both of us have had parents who go out of their way to create situations where we can make and be

with friends. Our social networks are important, Emma and I are both connected across the world with people who understand what it's like to use AAC. We don't want to only be connected to people who are part of the AAC community, but they are a source

of important support where we don't have to explain everything all the time.



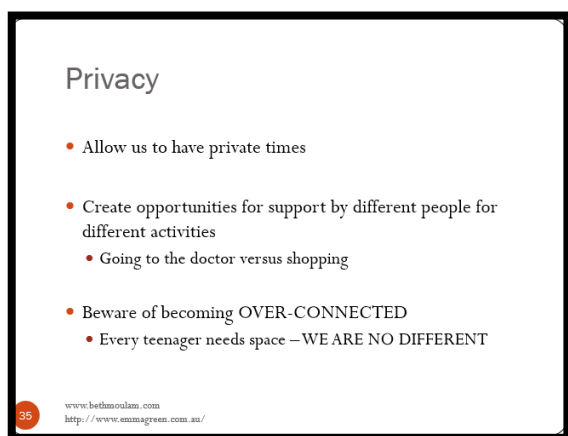
Role Models and Mentors

- Seek out role models (good and bad) in every part of life
 - These don't need to be people who use AAC
- Observe and understand their achievements, expectations and experiences
- Develop mentors with trusted individuals who will answer questions and share experiences freely
 - These don't need to be people who use AAC

34
www.bethmoulam.com
<http://www.emmagreen.com.au/>

Role models and mentors are vital for everyone. We are both fortunate to have some amazing people in our lives, but none of them live nearby.

Technology allows us to create and maintain these. As our relationships have developed with role models some have become mentors, people we can look to for advice and support rather than just observing their communication skills, lifestyle and experiences.



Privacy

- Allow us to have private times
- Create opportunities for support by different people for different activities
 - Going to the doctor versus shopping
- Beware of becoming OVER-CONNECTED
 - Every teenager needs space – WE ARE NO DIFFERENT

35
www.bethmoulam.com
<http://www.emmagreen.com.au/>

Balandin mentioned in her research the issue of privacy, being self-contained is an important part of connectedness. This is a tough one for people like Emma and myself. We need support 24 hours

a day. Whilst being connected is vital there is the risk of being over connected! We can have few secrets, little in our lives is

private. There is a balancing act to agree who supports us in what type of activities and when.

Gatekeepers

Whoever you are please

Before you make a decision for us – check what we want



www.bethmoulam.com
http://www.emmagreen.com.au/

36

Balandin also quoted gatekeepers as being important in developing friendships. People can unwittingly become barriers to being connected if they are unwilling, or unable, to get us to

places we want to go. Or, they make decisions on our behalf without consulting us in what we want. To quote an oft used phrase by disabled groups. 'nothing about us, without us'.

Connectedness is essential

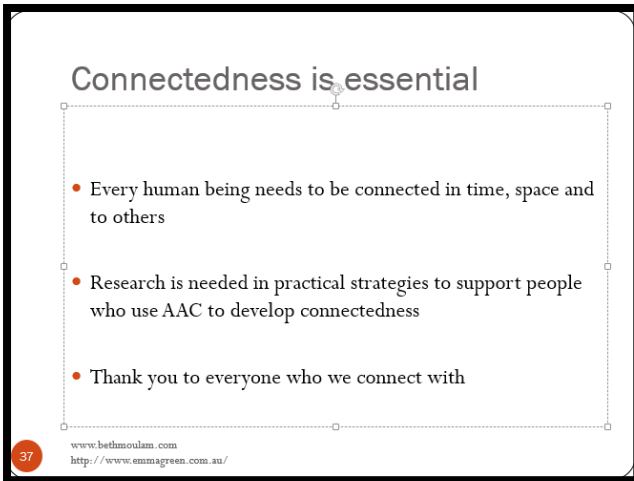
- Every human being needs to be connected
- Research is needed in practical strategies to support people who use AAC to develop connectedness
- Thank you to everyone who we connect with

www.bethmoulam.com
http://www.emmagreen.com.au/

37

These are just our personal views. If there are any academics here we would like to see further research in practical strategies in supporting children and young adults facing transition who use

AAC to develop connectedness.



In summary, it does not matter where we live, or if we use AAC, we all form connections with others, to places and a feeling of belonging in similar ways. Connectedness is vital for every

human being.

Meanwhile, we are grateful for our families and support workers who do an amazing job. And a special thank you to Emma, Bethany and Toni for coming all the way from Australia.



We will try and answer any questions but please be patient when asking Emma questions as she has to work with her mum to prepare her answer. Thanks for listening.

NOTES:

Beth Moulam

www.bethmoulam.com

Emma Green

<http://www.emmagreen.com.au/>

© Beth Moulam & Emma Green 2013